DOCUMENT RESUME

ED 252 051 EC 171 308

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TITLE Creating an Information Base for Program Collaboration. Workbook Series for Providing Services to Children with Handicaps and Their Families.
INSTITUTION Georgetown Univ. Child Development Center, Washington, DC.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE May 84
GRANT DHHS-PHS-MCJ-113368-01-1
NOTE 37p.; For related documents, see EC 171 305-307.
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Agency Cooperation; Community Programs; *Coordination; *Developmental Disabilities; Elementary Secondary Education; *Information Networks; *Information Services; *Program Development; State Programs
IDENTIFIERS Utah

ABSTRACT

This publication describes Utah's Handicapped Child Data Project, an interagency effort to share information among agencies dealing with developmentally disabled persons and establish a central registry. Five action steps in such a venture are noted, including identifying potential sources of information on state and individual levels, decreasing the use of jargon, signing agreements of understanding, and implementing an automated central data system. Three stages of information exchange are described and component steps reviewed: gathering information about an individual child, establishing program to program or agency to agency communication, and building a statewide system. The efforts of the Handicapped Child Data Project are reviewed in terms of history, organization, policies, and sample data screens. (CL)

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EC171308

WORKBOOK SERIES FOR PROVIDING SERVICES TO

CHILDREN WITH HANDICAPS AND THEIR FAMILIES

# CREATING AN INFORMATION BASE FOR

# PROGRAM COLLABORATION

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Edited by the editorial staff of the National Center for Education in Maternal and Child Health

May, 1984

EC171308

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## INTRODUCTION

The need to eliminate the gaps in service and to enhance communications between and among delivery agencies has long been recognized as an essential prerequisite to establishing a total service delivery model for highly vulnerable populations. In recent years, federal initiatives and the gradual eroding of resources, brought about by inflation, have given impetus to an increased interest in collaborative efforts between and among agencies in an attempt to meet the needs of developmentally disabled persons.

An interagency project in Utah called the Handicapped Child Data Project has clearly established the need for improvement in communication among agencies through:

- o better communication between disciplines, especially between medical personnel and educators;
- o better ways of providing a cumulative history as a developmentally disabled person proceeds through each agency's system;
- o better planning for future needs--preservice to early intervention, early intervention to preschool, preschool to school, school to vocational education;
- o a quick and effective way of directing those seeking help to others with the same intent.

These needs suggest as a solution a computer-assisted information management system.

Each agency providing services to handicapped individuals collects and utilizes client-specific information which relates to the scope of services offered. By making information of common interest available across the spectrum of providers, not only can current services be provided more efficiently, but unmet needs can also be recognized and accommodated through improved planning.

This common information (basic demographic data, services currently being received, service providers, the functional nature of the disability, and the estimates of services needed) is essential to the needs of all service agencies involved or likely to become involved.

<u>While each agency requires agency-specific individual client information to program the delivery of its unique services, all agencies need common (and shared) information if a comprehensive service delivery model is to be established to meet the needs of this ever changing, highly vulnerable population.</u>

Basic interagency data are essential for discipline-specific research. The following are needed and require shared data from providers: research involving interdisciplinary correlation studies, etiology studies, and studies of service delivery models best meeting the needs of the disabled living in rural areas as well as in urban centers.

Incidence data derived from a sample of the general population cannot provide adequate information for planning of individual service needs. Such samples of data seldom meet the needs of a particular state, or area within a state, and almost never satisfy legislators who make resources available through appropriation of funds. Gathering data from primary sources (i.e., the developmentally disabled and/or their families or other caretakers) appears to be the only way an adequate total service delivery model can be systematically planned, developed, and evaluated.

Convergence of the suspected incidence and the true incidence regarding the developmentally disabled/handicapped population may never be possible. Working from known data generated from primary sources is, however, a prerequisite to establishing a service delivery case management system. The goal is a total service delivery system amenable to changes as needs evolve. Changes are prompted by shifting legislative mandates which reflect fluctuating economic conditions, philosophies, and social trends. To reach the goal of a total service delivery system, or even a minimally acceptable one, a central registry for developmentally disabled and handicapped persons is essential.

This workbook discusses practical intermediate steps for sharing data, as well as the necessary steps for establishing a central registry.

## RESULTS OF A STUDY ON INFORMATION EXCHANGE

The Handicapped Child Data Project was an interagency effort funded by the Office of Maternal and Child Health with a goal to "facilitate the transfer and usefulness of data generated and gathered by preschool programs and health agencies serving handicapped children to school districts' special programs, thereby improving the educational outcome for the handicapped child." Facilitating this transfer of information would enhance the working relationships among agencies serving the handicapped child--such improvement was hoped to become a standard.

There are four important conclusions that can be deduced from this project that have influenced the development of this workbook.

1. Over a lifetime a great deal of information accumulates about a child; this process begins prior to birth (Fig. 1). Sometimes this information is helpful; sometimes it is contradictory, obscure, incomplete, and useless; sometimes it can be shared. In fact, there is no consistent, reliable sharing of pertinent information among those people (sometimes even the parent) trying to help the child.

2. The method of information exchange--therefore its usefulness--varies greatly among the professionals collecting the data. Reports by psychologists, developmental specialists, speech therapists, physical therapists, occupational therapists, and nutritionists tend to be very communicative. Reports between physicians also are communicative to doctors, but are often not helpful to others. Reports by audiologists are sometimes understandable, sometimes not. Reports from vision specialists are nonexistent. Summary reports by teams--when they exist--tend to be the most helpful of all reports in the chart.

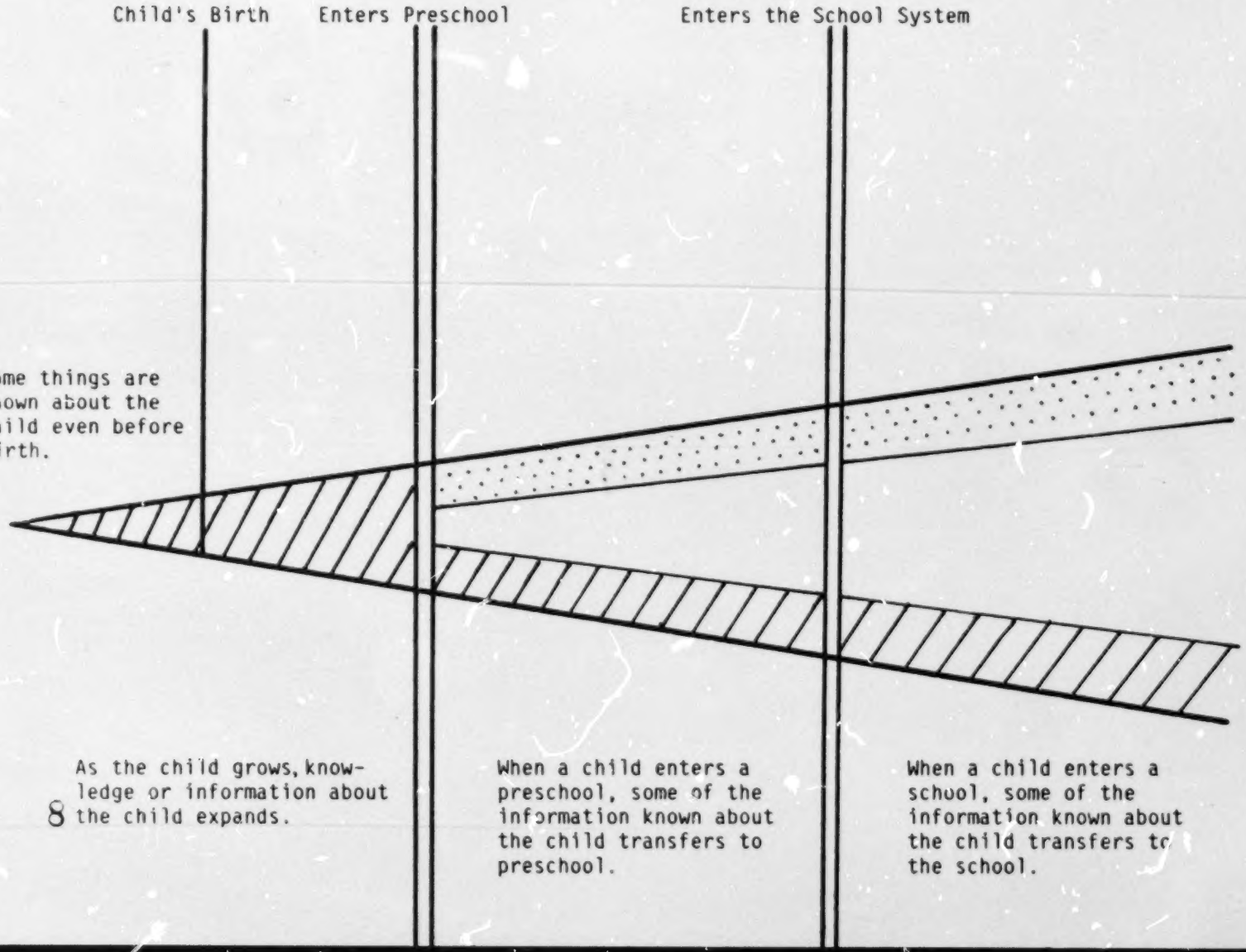
3. The value of information exchange depends upon not only the sender, but also the receiver. Attitudes of those receiving information are very important. If a professional wants specific information, and takes an active role in obtaining it, it is usually obtainable.

4. The only person that consistently sees the client/child through the whole process therefore a key in information exchange--is the parent.

As a result of these findings and following discussions with other professionals, these action steps emerged:

Figure 1

INFORMATION GROWTH ABOUT A CHILD


Child's Birth
Enters Preschool
Enters the School System
Some things are known about the child even before birth.
As the child grows, knowledge or information about the child expands.
When a child enters a preschool, some of the information known about the child transfers to preschool.
When a child enters a school, some of the information known about the child transfers to the school.

Color Key

Information known by the preschool or school.

Information known by others, such as MD's, parents or health agencies.

Important information shared by all agencies.

ACTION STEP #1: IDENTIFY POTENTIAL INFORMATION SOURCES ON A STATE LEVEL. A central information center listing all groups, agencies, and programs for handicapped children needs to be developed. This listing should include:

a. The name of the entity and a description (i.e., the Children's Nest, a preschool serving emotionally disturbed infants and children, ages 0-3);

b. A brief description of the program (i.e., a special federally funded demonstration project providing intensive one-to-one help on a daytime basis only);

c. A contact person, address, and telephone number;

d. A complete description of the population served;

e. Other relevant information such as fees charged, qualifications of staff, accreditations, affiliations with universities, etc.

This task can be accomplished by collecting the data using Worksheet 1.

ACTION STEP #2: IDENTIFY INFORMATION ON AN INDIVIDUAL LEVEL. One must begin to build an information base by constantly asking anyone associated with the child where services have been provided and by whom. A standard format should be developed to assist both parents and professionals in keeping track of this information (see Worksheet 2). In this effort to keep individual information, it was found to be neither helpful nor possible to keep anything more than the most essential information: (a) information that would alert others to serious conditions, and (b) information that would direct others to the primary sources for that information.

Clearly, direct contact among agencies was the most effective method of information exchange for an individual.

Worksheet 1

Information Source for Handicapped Children

Name of Agency/Program: _____

_____

Type of Program/Population Served: _____

_____

Brief Description: _____

_____

_____

Contact Person: Name _____

Address _____

_____

Phone _____

Fees: _____

Qualifications of Staff: _____

_____

_____

Other (Accreditations, University Affiliations, etc.) _____

_____

Complete Description of Program: _____

_____

_____

Worksheet 2

**UTAH STATE OFFICE OF EDUCATION & UTAH DEPARTMENT OF HEALTH**

# COMPREHENSIVE ASSESSMENT RECORD

**FOR COMPILING AND TRANSFERRING DATA ON HANDICAPPED CHILDREN**

To Parents, Preschools, Schools, Health and Social Agencies:
1. A master copy of this form should be kept in the student files and become a permanent part of the record.
2. This form should be sent each time there is an exchange of information between agencies.

NAME OF CHILD _____ SEX _____ BIRTHDATE _____
PARENT(S) OR GUARDIAN(S) NAME(S) _____ PHONE _____
ADDRESS _____ ZIP CODE _____
PRIMARY LANGUAGE OF THE HOME _____ OF THE CHILD _____

**AGENCIES THAT HAVE WORKED WITH THIS CHILD:**

| AGENCY, CLINIC, PHYSICIAN OR SCHOOL | CONTACT PERSON | DATE OF SERVICE | DIAGNOSIS OR EDUCATIONAL CLASSIFICATION |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

## HEALTH

| TYPE OF EVALUATION | DATE | IMPAIRMENT YES | IMPAIRMENT NO | ADMINISTERING AGENCY | DATE | IMPAIRMENT YES | IMPAIRMENT NO | ADMINISTERING AGENCY |
|---|---|---|---|---|---|---|---|---|
| DENTAL | | | | | | | | |
| NURSING | | | | | | | | |
| NUTRITIONAL | | | | | | | | |
| PHYSICIAN'S | | | | | | | | |
| MEDICAL SPECIALIST _____ | | | | | | | | |
| _____ (specify type) | | | | | | | | |

| | PRIMARY DIAGNOSIS | SECONDARY DIAGNOSIS | DATE OF DIAGNOSIS | DIAGNOSING PARTY |
|---|---|---|---|---|
| SPECIFY ANY HANDICAP DIAGNOSED | | | | |
| | | | | |
| | | | | |

| | | DATE PRESCRIBED | PRESCRIBING PHYSICIAN |
|---|---|---|---|
| DOES A CHRONIC CONDITION EXIST THAT REQUIRES MEDICATION? | YES ___ NO ___ | | |
| | YES ___ NO ___ | | |
| | YES ___ NO ___ | | |

| | | DATE PRESCRIBED | SPECIFY TYPE | PRESCRIBED BY |
|---|---|---|---|---|
| IS SPECIAL EQUIPMENT NEEDED? | YES ___ NO ___ | | | |
| | YES ___ NO ___ | | | |
| | YES ___ NO ___ | | | |

## HEARING

| | DATE | IMPAIRMENT YES | IMPAIRMENT NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | IMPAIRMENT YES | IMPAIRMENT NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| BEHAVIOR OBSERVATION | | | | | | | | |
| IMPEDENCE AUDIOMETRY | | | | | | | | |
| PURE TONE AUDIOMETRY | | | | | | | | |
| SPEECH AUDIOMETRY | | | | | | | | |
| OTHER _____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

## VISUAL

| | DATE | IMPAIRMENT YES | IMPAIRMENT NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | IMPAIRMENT YES | IMPAIRMENT NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| SNELLEN | | | | | | | | |
| KOHS | | | | | | | | |
| OTHER _____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

## ACADEMIC/READINESS

| | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| ABC INVENTORY | | | | | | | | |
| BEREITER-ENGLEMAN | | | | | | | | |
| OTHER_____ | | | | | | | | |
| _____ | | | | | | | | |

## COMMUNICATIVE

| | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| ARTICULATION | | | | | | | | |
| EXPRESSIVE LANGUAGE | | | | | | | | |
| RECEPTIVE LANGUAGE | | | | | | | | |
| FLUENCY | | | | | | | | |
| VOICE | | | | | | | | |
| OTHER_____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

## DEVELOPMENTAL

| | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| ALPERN-BOLL DEVELOPMENTAL | | | | | | | | |
| BAYLEY SCALES | | | | | | | | |
| BRIGANCE PRESCHOOL | | | | | | | | |
| DDST | | | | | | | | |
| GESELL | | | | | | | | |
| McCARTHY SCALES | | | | | | | | |
| OTHER_____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

## INTELLIGENCE

| | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| BAYLEY | | | | | | | | |
| STANFORD-BINET | | | | | | | | |
| WPPSI | | | | | | | | |
| OTHER_____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

## MOTOR ABILITIES

| | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| BENDER-GESTALT | | | | | | | | |
| BRUININKS-OSERETSKY | | | | | | | | |
| MELANI-COMPARETTI | | | | | | | | |
| SOUTHERN CALIFORNIA TEST | | | | | | | | |
| NON-STANDARDIZED ASSESSMENT | | | | | | | | |
| OTHER_____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

## SOCIAL/EMOTIONAL/BEHAVIORAL

| | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY | DATE | DELAY YES | DELAY NO | NAME OF SCHOOL, CLINIC OR AGENCY |
|---|---|---|---|---|---|---|---|---|
| BURKS-BEHAVIOR RATING | | | | | | | | |
| LOUISVILLE BEHAVIOR RATING | | | | | | | | |
| NON-STANDARDIZED ASSESSMENTS | | | | | | | | |
| OTHER_____ | | | | | | | | |
| _____ | | | | | | | | |
| _____ | | | | | | | | |

**COMMENTS**

Copies may be obtained from the Handicapped Child Data Project at:

UTAH STATE DEPARTMENT OF HEALTH
Division of Family Health Services
44 Medical Drive, Salt Lake City, Utah 84113
533-6031 533-6161

UTAH STATE OFFICE OF EDUCATION
Special Education Section
250 E. 500 S., Salt Lake City, Utah 84111
533-5982

ACTION STEP #3: DECREASE THE EFFECTS OF "LANGUAGE BARRIER" SYNDROME. Perhaps nowhere is this need more evident than between educators and physicians. The standardized form (Worksheet 3) was designed to aid communication among educators and physicians, vision specialists, and audiologists. The form is currently being used extensively in several school districts as a means both of assisting educators to request information in terms medical professionals find acceptable and, therefore, of assisting medical professionals to respond in terms understandable to educators.

ACTION STEP #4: SIGN AGREEMENTS OF UNDERSTANDING. While memoranda of understanding have incurred some disfavor, they can still be helpful or even essential in certain areas. Conflicts may arise between agencies because of perceived differences in the application of rules and regulations. This conflict should be confronted directly once agreement has been reached; that agreement should be in a written and signed form.

ACTION STEP #5: IMPLEMENT AN AUTOMATED CENTRAL DATA SYSTEM. The most effective means of coordinating and sharing data comes from the use of an automatic system available to each agency or individual with a legitimate need. These systems are often called central registries.

The most valuable and useful information to an agency is self-generated. The biggest challenge to the effective sharing of information is not the mechanical exchange of data, but rather the elimination of barriers causing agencies to see each other as "those other agencies." A basic legal premise, making a central registry possible, is that information about handicapped individuals is not owned by agencies--certainly not by the individuals in those agencies. It is a resource which must be made available to those with a legitimate right or need to know. That right is created when a client makes a valid request for service to an agency of the state and that information is needed in order to provide the service. The rights of privacy and confidentiality are not compromised by the rights of children to appropriate service.

UTAH DEPARTMENT OF HEALTH & UTAH STATE OFFICE OF EDUCATION

Worksheet 3

# REQUEST FOR DIAGNOSTIC INFORMATION FOR SPECIAL EDUCATION

**This form is intended to be used by schools and preschools when requesting information from professionals who have completed evaluations on the student. The section marked education is to be filled out by the requesting party and subsequent sections are to be filled out by the professionals indicated for each section.**

Sent to _____ Date of request _____ Date returned _____

Name of Student _____ Sex ____ Birthdate _____
Parent(s) or Guardian(s) Name(s) _____ Phone _____
Address _____ Zip _____
School or preschool requesting information _____
Address _____ Zip _____ Phone _____
Contact Person _____ Title _____ Signature _____

**PURPOSE OF REQUEST** ☐ Evaluation ☐ Classification ☐ Individualized Ed. Program ☐ Placement ☐ Daily Management

Description of the Presenting Problem: _____

**CURRENT FUNCTIONING IN RELATIONSHIP TO NORMAL CHILDREN**

| Area | Above | Average | Below |
|---|---|---|---|
| Academic/Readiness | | | |
| Adaptive Behavior | | | |
| Emotional/Behavioral | | | |
| Language/Speech | | | |
| Motor (fine and gross) | | | |
| Self Help | | | |
| Social | | | |

**CURRENT SPECIAL EDUCATION PLACEMENT**

___ Not Yet Placed
___ Preschool-Homebased
___ Preschool-Centerbased
___ Regular Classroom
___ Resource
___ Self-contained
___ Special Day School
___ Residential School
___ Homebound/Hospital

Educational Diagnosis/Classification _____

**OTHER SERVICES CURRENTLY PROVIDED BY SCHOOL**

___ Audiology ___ Occupational Therapy ___ Psychology ___ Speech Therapy
___ Nursing ___ Physical Therapy ___ Social Work ___ Vision Screening
Other (please specify) _____

**EDUCATION REQUESTS THAT THE FOLLOWING SECTIONS BE COMPLETED:**

☐ **Physician** ☐ **Vision Specialist** ☐ **Audiologist** ☐ **All Specialists** ☐ **Comments and Recommendations**

1. What are this child's specific medical diagnoses? _____
2. List any conditions that might interfere with school performance: _____
3. List any known allergies (food, medications, environmental conditions, etc.): _____
4. Is the student taking medications: ☐ Yes ☐ No If yes, please fill in information below.

| | 1 | 2 | 3 |
|---|---|---|---|
| Name of Medication(s) | | | |
| Condition prescribed for | | | |
| Dose | | | |
| Form | | | |
| Stop date | | | |

Do any of the medications need to be taken at school? ☐ Yes ☐ No **Name of Medication(s):** _____
List significant side effects that might affect school performance: _____

5. Does the student's condition require special equipment? ☐ Yes ☐ No Specify Type: _____
Should equipment be used at school: ☐ Yes ☐ No Limitations on use: _____
Instructions for management: _____
6. Do any of these conditions require that school activities be limited or modified? ☐ Yes ☐ No Please explain: _____

**Physician's Signature** _____ Date _____ Phone _____

**(Refer to questions 17 and 18, over)**

7. List any diagnosed visual problems: _____
   Specify cause: _____
   Age of onset: _____ Is this condition progressive? ☐ Yes ☐ No
8. The child's corrected visual acuity is: ☐ Right eye ☐ Left eye
9. Can the child visually track? ☐ Yes ☐ No
10. Child's field of vision is: _____
11. Do any of these conditions interfere with the child's learning? ☐ Yes ☐ No Please specify: _____

**Examiner's Signature** _____ Date _____ Phone _____

12. List any diagnosed hearing problems: _____
    Specify cause: _____
    Age of onset: _____ Is this condition progressive? ☐ Yes ☐ No
13. Was an audiometric test completed? ☐ Yes ☐ No Indicate type of loss and degree in DB:
    ____ Conductive ____ Right ear ____ Left ear
    ____ Sensorineural ____ Right ear ____ Left ear
    ____ Mixed loss ____ Right ear ____ Left ear
14. Was an impedence test done: ☐ Yes ☐ No Indicate results: ☐ Right ear ☐ Left ear
15. Can the child: Attend to auditory stimuli? ☐ Yes ☐ No
    Respond to auditory stimuli? ☐ Yes ☐ No
    Localize sounds? ☐ Yes ☐ No
16. Do any of these conditions interfere with auditory learning? ☐ Yes ☐ No Please specify: _____

**Examiner's Signature** _____ Date _____ Phone _____

17. Are any diagnostic procedures or surgeries pending? ☐ Yes ☐ No Please specify type: _____
    Date _____ Instructions to the school _____
18. Please indicate reports that are available from your agency or clinic:
    ____ Dental ____ Nutrition ____ Physical Therapy ____ Speech Therapy
    ____ Neurology ____ Occupational Therapy ____ Psychology ____ Discharge Summary
    ____ Nursing ____ Orthopedic ____ Social Work ____ Staffing Summary
    Other (please specify) _____

**COMMENTS OR RECOMMENDATIONS:**

**Copies may be obtained from the Handicapped Child Data Project at:**

UTAH STATE DEPARTMENT OF HEALTH
Division of Family Health Services
44 Medical Drive
Salt Lake City, Utah 84113
533-6031 533-6161

OR

UTAH STATE OFFICE OF EDUCATION
Special Education Section
250 East 5th South
Salt Lake City, Utah 84111
533-5982

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## THREE STAGES OF INFORMATION EXCHANGE

I. Gathering Information About An Individual Child
II. Establishing Program to Program or Agency to Agency Communication
III. Building a Statewide System

In order to best serve each handicapped child all pertinent information about that child must be available in one location. Information about a child is often fragmented among services provided by a variety of agencies and professionals. A consistent, comprehensive, and rational system of child-centered information exchange is needed. Unfortunately, in most states, such a system does not exist. However, the individual service provider should not give up.

While the ideal may be to establish multiagency, systematic, automated statewide information exchange, there are useful and productive intermediate steps--steps that would continue to remain useful in the development of an automated system.

THE FIRST STAGE: Gathering Information About An Individual Child

In most instances one needs information during the direct meeting with the child. A parent presents a child to your program. It is then most tempting to proceed as if the child has had no past. This case is rarely true. The first level of constructing a client information exchange system begins at this point with the individual child.

The following steps will help direct your search for information:

1. Find out where the child has been served.
2. Make contacts and use them to develop further contacts.
3. Begin the formal process of gathering information.
4. Interpret and use what you receive.

The parents are your best source of information about who has previously seen the child. If time were not a factor, formal letters of inquiry with parental permissions might be sent, not only to those agencies the parents remember, but also to other probable service sources. Generally, you do not have the luxury of weeks for a reply. So while the parent is there, call to confirm that the child was actually seen and served at various agencies the

parents may mention. Suggest others and don't be afraid to call both doubtful sources and confirmed ones. The essential items of information from these calls are:

1. A contact person who may best gather all information for you;
2. Dates of service--precise as possible;
3. Types of services provided (general, not necessarily specific);
4. Reports that may be copied and sent; other information might be available in another form;
5. Other service providers (with a contact name, if possible) who might be known.

When you have gathered this information, ask the parent to sign release-of-information forms. Then write for information; be as specific as possible--with the basis of the information you collected. If reports are available, they are generally most helpful when copied in their entirety. However, in some cases, there are no reports. Then you must be very specific in asking the questions you wish answered. Worksheet 3 is an example of a form that can be used.

This type of form can be used in at least three different ways, each of which is progressively more effective.

a. The parent or guardian of the child keeps the record and therefore has a hard copy of all programs and services received by their child. This record may be copied anytime the child enters a new program.
b. An individual program may keep the record for its own use to monitor the child as the parent does. This record may be copied and sent with the official record when the child transfers.
c. All programs may cooperate in keeping such a record current; thereby you ensure coordination of information and effort.

For interpretation of material received, ideally a professional in the area in question should review the material and then make contact with the sending professional. This procedure is not always possible. Much time, effort, and appropriate treatment have been lost in attempting to serve a child when valuable information has been disregarded because the receiver was not qualified to understand the implications of what was received.

Finally, remember to apply the golden rule. Be willing to go out of your way to supply information on a child to others.

HAVE YOU PROVIDED?

___ a. A name, phone, and address for a contact person for that child;
___ b. A listing of the types of information you have on the the child and the form in which it can be shared;
___ c. The dates on which you provided service;
___ d. The names of others that you know of who have served the child;
___ e. Any of your major or serious concerns that should be "red-flagged."

Either give this information in written form to the parent to pass on, or else send it with written parental permission to the program where the child is going.

THE SECOND STAGE: Establishing Program to Program or Agency to Agency Communication

It does not take many individual cases, such as that described, to facilitate understanding of the value of establishing more consistent and permanent relationships with other agencies or programs (See Workbook -- Power Brokering at the Community Level). If you have regular exchanges between programs or agencies, establish them formally. Often we fail to apply interactions necessary for one child to help us with the next.

Often these questions are asked:

1. Who is responsible?
2. Who should take the initiative?

The answers to both of these questions is YOU. Whoever you are, whatever agency you represent, whatever profession you have--if you are reading this workbook, you are the one! It really does not matter who starts it. Take the initiative; make something good happen.

Build good personal contacts. In this bureaucratic world, the best information exchange still happens between people. Go out of your way to help others look good. Be personable, helpful,

friendly. In other words, develop good personal working relationships. Even though goodwill often prevails, these gains are not always perpetuated. Use these personal relationships as models to establish good information exchange systems.

Learn to speak as many jargons as possible. Educators should learn to understand medical terms, medical professionals should learn to understand social workers, and everyone should learn to understand parents. Be a good listener. If an interpreter is necessary, get one.

In working towards developing written agreement, write down:

1. What you do;
2. When you do it;
3. How you do it.

All participants to the agreements should sign them. You may want them as formal as possible so that later written precedents of cooperation will endure. It is often asked: at what level should these agreements be signed? The answer is at all and every level possible. There is no single "right way" to do it. Sometimes it works to begin at a low level and work up. Other times the opposite works. Find others who will cooperate; establish in writing with each person whatever level of cooperation you can achieve.

THE THIRD STAGE: Building a Statewide System

In many ways, coordinating at the state level is the most difficult of the three (See Workbook - Power Brokering at the State Level). Gone is the closeness and informality of the parent-teacher-child triad found at the first stage. Even in the communication of program to program a personal element results from working relationships among peers. At the state level, one is dealing with many layers of bureaucracy, red tape, protocol and past history. You may ask yourself:

1. Where do we begin?
2. Who should initiate the action plan?

Let's begin with the second question first. Any agency, parent or advocacy group can begin the process, and the process begins by bringing key participants together.

Plan an initial meeting, and decide on its purpose and intended goals. The goal may be:

| | |
|---|---|
| Goal: | To identify, collect, and make available to all involved service providers, for the purposes of program collaboration, an information base for each handicapped and at risk child (0-3) and family by _____, 19__. |

After the purpose of the meeting is established, you can draw up a list of key participants. These participants should be those with the authority to make decisions in the attainment of your goals.

The agenda of the initial meeting should include the identification of:

1. Actions needed to create an information base;
2. Persons to help create an information base;
3. Timelines for creating an information base.

ACTIONS NEEDED TO CREATE AN INFORMATION BASE CHECKLIST

___ 1. Information gathering - collect forms, telephone key service providers - find out what's available.
___ 2. Identify data sharing currently being done and by whom.
___ 3. Establish a common information base from what's available.
___ 4. Establish common information needs.
___ 5. Identify information needs currently not available from any source.
___ 6. Assign responsibility for collection of needed information through group process.
___ 7. Develop a common information form to be used by all service providers and/or central registry.

## PERSONS TO HELP CREATE AN INFORMATION BASE CHECKLIST

___ 1. Be sure to involve and receive sanction from key decision-makers from lead agencies at the beginning and end of the project.

___ 2. Identify key service providers with access to many parents.

___ 3. Assign data collection responsibility appropriately.

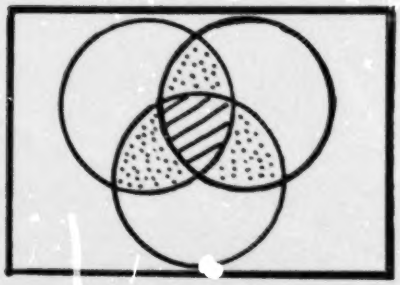
Example: A Head Start representative should contact other Head Start personnel and ascertain their needs, inquire about the types of information they currently require, and collect examples of their information forms.

## SAMPLE TIMELINES FOR CREATING AN INFORMATION BASE

1. By October 19__ the initial planning meeting will take place. Responsible parties: key decision-makers from lead agencies.
2. By January 19__ all information gathering will be completed and forms/interview material collected. Responsible parties: key service provider representatives.
3. By February 19__ a meeting to establish common information needs and gaps will take place. Responsible parties: key service provider representatives are essential, key decision-makers from lead agencies are optional.
4. By April 19__ all needed information will be collected in systematic fashion by persons so assigned.
5. By May 19__ a meeting to develop a common information form and/or central registry computer program to be used by all service providers will take place. Responsible parties: Key service provider representatives and key decision-makers from lead agencies.

To help your participants identify information sources and begin collecting information, you might try the following steps:

1. Have each participant help fill in the following chart using data being currently collected.



Common Info. From All 3 Sources
Common Info. Between 2 Sources
Info Unique to 1 Source

2. Have the participants study the chart and identify those data available, but not currently shared. A new chart can then be developed placing information needed by all service providers in the appropriate area on the chart (Figure 2).

3. Next, have participants identify information not represented on the charts, but valuable. Sources for that information should be identified and persons selected to develop a system for collection.

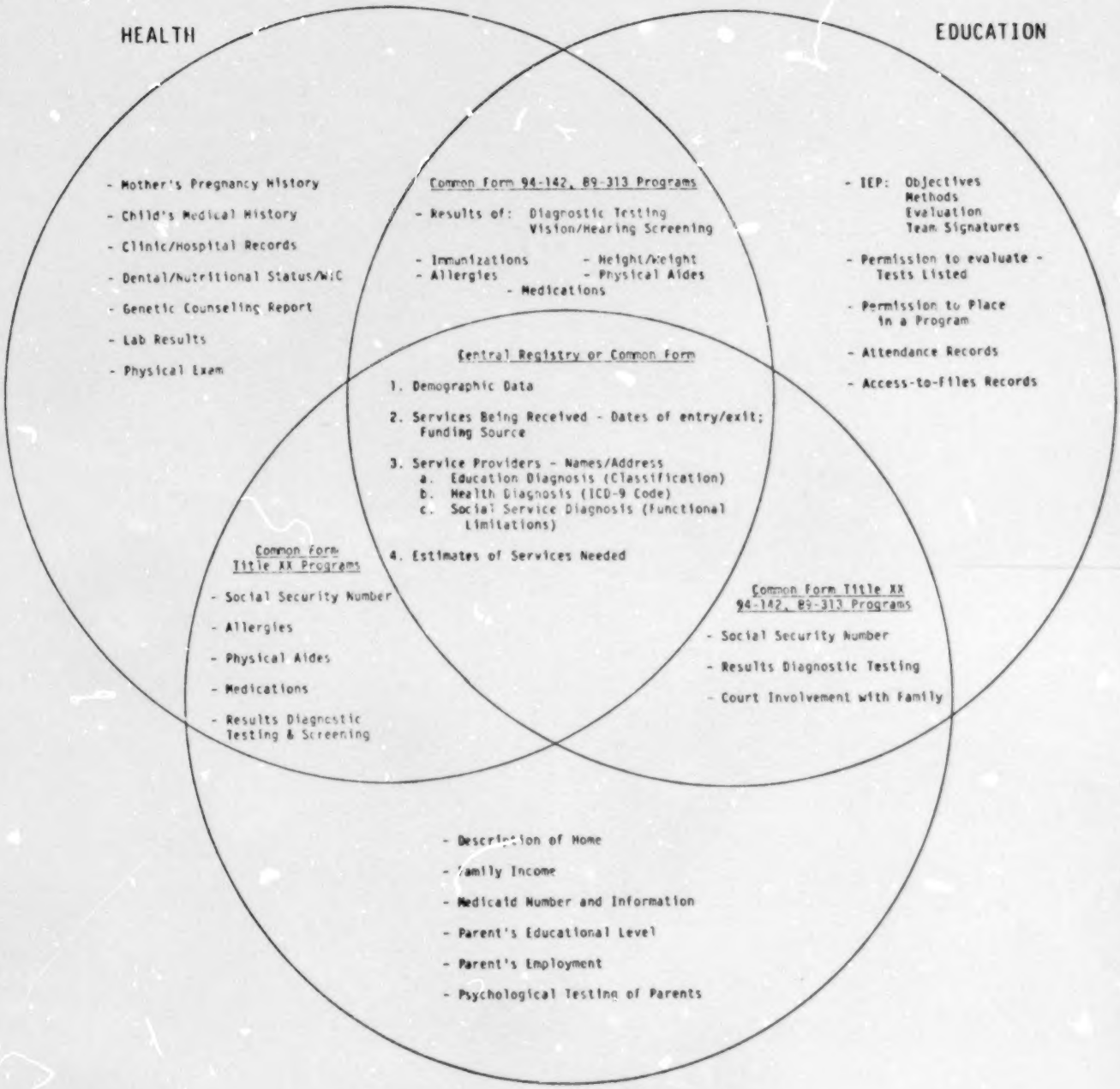
Subsequent meetings should follow the timeline established in the initial meeting. Each new meeting should develop its own action plan to include:

1. Actions needed.
2. Persons to undertake the actions.
3. Timelines for actions to be undertaken.

Finally, keep your goals in mind. If your goal was similar to the example given be sure your action plan includes steps specific to its attainment. These steps may be to:

Figure 2

## INFORMATION COLLECTED BY HEALTH, EDUCATION AND SOCIAL SERVICES



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SAMPLE ACTION STEPS

1. Plan one of the meetings to develop a common information form and/or central registry computer program to be used by all service providers.

b. Identify at that meeting a lead agency or multi-agency case management group to be responsible.

c. Form a concensus on the population to be served.

Population can be broken down by:

1. age
2. education diagnosis (classification)
3. health diagnosis (ICD-9 Code)
4. social diagnosis (functional limitations)
5. family income
6. school district/health district
7. urban/rural

4. Identify the uses to which the information will be put.

5. Draw future implications for interagency program collaboration through information sharing (long-term goals) about the following board topics: funds, training provided, personnel available, standards and certification, agency action plans (see Figure 3).

If your action plan goes smoothly, the final outcome of your statewide system should be the attainment of your goals and the written policy to support it. Bonne chance!

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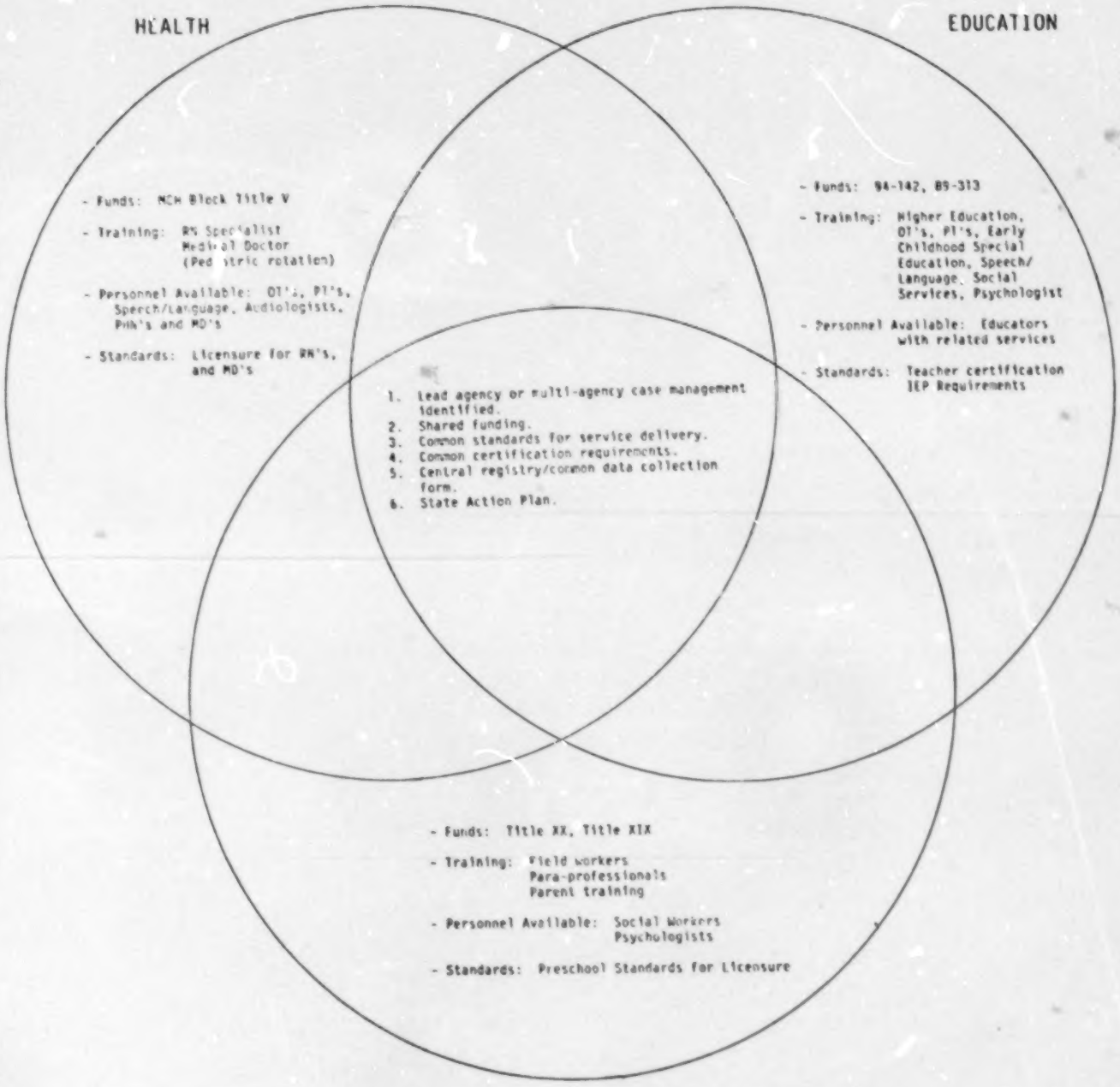
Figure 3

## INFORMATION SHARING FOR PROGRAM COLLABORATION


HEALTH
- Funds: MCH Block Title V
- Training: RN Specialist
Medical Doctor
(Pediatric rotation)
- Personnel Available: OT's, PT's, Speech/Language, Audiologists, PHN's and MD's
- Standards: Licensure for RN's, and MD's
EDUCATION
- Funds: 94-142, 89-313
- Training: Higher Education, OT's, PT's, Early Childhood Special Education, Speech/ Language, Social Services, Psychologist
- Personnel Available: Educators with related services
- Standards: Teacher certification IEP Requirements
1. Lead agency or multi-agency case management identified.
2. Shared funding.
3. Common standards for service delivery.
4. Common certification requirements.
5. Central registry/common data collection form.
6. State Action Plan.
- Funds: Title XX, Title XIX
- Training: Field workers
Para-professionals
Parent training
- Personnel Available: Social Workers
Psychologists
- Standards: Preschool Standards for Licensure
SOCIAL SERVICES

## BUILDING A CENTRALIZED AUTOMATED SYSTEM OF INFORMATION EXCHANGE

I. A Brief History of Utah's Effort
II. Organization
III. Policies
IV. Data Screens

### A BRIEF HISTORY OF UTAH'S EFFORTS

The need for an interagency registry of developmentally disabled and handicapped persons was recognized in the early 1970s. The first attempt to establish such a registry began in 1975 prior to the passage of P.L. 94-142 (Education for All Handicapped Children Act) and P.L. 95-602 (Developmental Disabilities Assistance and Bill of Rights Act). The initial effort involved several man-years; policies and procedures were suggested, data elements identified, and interagency cooperation solicited.

The first attempt was never implemented for a variety of reasons. Among these were:

1. a lack of motivation on the part of state and local service providers to initiate the project,

2. a lack of resources,

3. data elements identified were viewed as being single agency-specific, and

4. at the time, there was no statutory authority for the sharing of personally identifiable information.

The need remained unmet. Data files in the Department of Health, Education, and Social Services remained the "property" of the agency generating the data.

The seeds planted in 1975 lay dormant for several years. During this time, several changes occurred:

1. The passage of P.L. 94-142 and P.L. 95-602 required cooperative agreements between and among the agencies to improve the delivery of services to the handicapped and developmentally disabled;

2. The Utah Legislature passed the Health Statistics Act providing for the sharing of personally identifiable information that is legally mandated to be collected between agencies and others with specific need to know;

3. Significant gaps in the service delivery system began to appear and data were not available to substantiate the extent to which clients' needs were not being met; and

4. The most pervasive concern was an increase in the demand for services in the face of declining resources. The State's population growth from 1,059,000 in 1970 to 1,461,837 in 1980 represented a 37.9% increase. With this increase in the general population came a proportionate increase in the number of handicapped and developmentally disabled.

These changes brought about a recognition by education and human service agencies that a central data source was essential to provide: non-duplicative enumeration of, and thus services to, the developmentally disabled and handicapped. The Handicapped Child Data Project, a joint Health and Education effort, identified establishment of a Central Registry as a primary solution to the problems of interagency data transfer. The time had come for creating and maintaining a central registry useful and accessible to each of the agencies involved.

During Summer 1981, a proposal to develop the interagency registry for the developmentally disabled and handicapped persons was written by a staff member of the Exceptional Child Center, a program affiliated with Utah State University. The proposal was subsequently funded by the Administration on Developmental Disabilities in the Department of Health and Human Services as a Project of National Significance. Though the registry was recognized as state-specific, it could serve as a model for other states facing similar problems in providing services.

The project was funded and a Cooperative Joint Policies and Procedures Management Board representing concerned agencies was established. Representatives from the Departments of Health, Social Services and Education (including the Division of Rehabilitation), the Utah Council for Handicapped and Developmentally Disabled Persons, and the Legal Center for the Handicapped devoted many hours to the project. Staffing of the project came from the Exceptional Child Center at Utah State University. Lacking adequate funds for computer systems design work and necessary computer programming, the agencies shared equally in providing manpower and fiscal resources to ensure the success of the project.

At the present time, the data elements included in the registry have been recommended as well as the policies and procedures under which the registry will operate. The problems of protecting confidentiality and individual rights to privacy have been largely worked out. (Utah's foresight in passing the Health Statistics

Act, Section 26-3-1 through 26-3-10 U.C.S. 195, providing the statutory basis for interagency sharing of personally identifiable information cannot be underestimated.)

In addition, an informal opinion by Utah's Attorney General was very helpful.

OPINION

"It is my opinion such a registry is not prohibited by law so long as:

a. The registry is duly created by appropriate legal process.

b. The collection of data by the participating agencies to be contained in the registry is made only in the furtherance of statuable authorized programs (Collection Stage).

c. Appropriate safeguards are maintained to protect such data from unauthorized access. (Storage Stage).

d. Close supervision is maintained to assure that the registry data is used by the interchanging agency only in the administration of lawfully authorized service programs for the disabled and handicapped in which the using agency is involved (Disclosure Stage)."

The initial model will extract information from existing data files. As experience with the data file dictates, additional data elements may be included: data elements thought to be of value but lacking in utility or only obtainable at excessive cost will be eliminated. The information will be available to agency personnel with a legitimate need to know. All personnel having access to the file will have entered into a written agreement as required in Utah Law.

By cooperative agreement, the Joint Education/Social Services/Health Coordinating Committee has identified the Utah State Office of Education as the most logical physical location for the data file. The operation and management of the file will remain under the Joint Education/Social Services/Health Coordinating Committee to ensure that the files remains useful to all agencies concerned.

ORGANIZATION

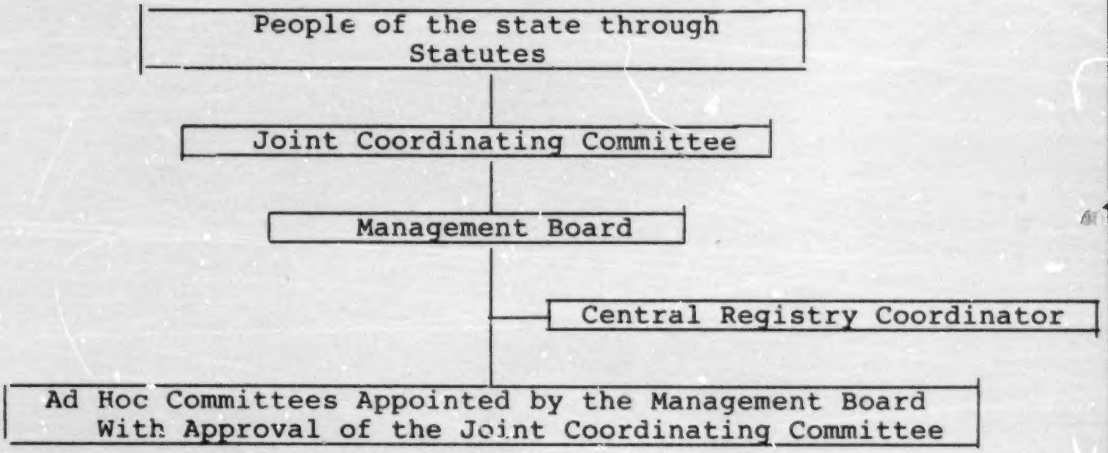
The term "handicapped" includes those individuals who qualify for services under P.L. 95-602, (Developmental Disabilities and Bill of Rights Act), P.L. 94-142 (Education of All Handicapped Children Act), and other state and federal statutes which provide for the delivery of health, education and social services to individuals who suffer from a handicap or other disabling condition and require interagency services in order to make them as functionally independent as possible within the limits of their handicaps.

The Central Registry should be an entity administered by a Joint Coordinating Committee. The purpose of a Central Registry is:

1. to provide a coordinated interagency management information system to meet the needs of agencies providing services to the developmentally disabled and handicapped persons of the State;
2. to provide data to meet the needs of research and policy development for the elimination of gaps in the service delivery system;
3. to reduce the incidence of diseases that result from developmental disabilities and handicapping conditions;
4. to increase mutual understanding of the interagency relationships required to provide for the needs of this population.

A Central Registry can be sanctioned through a wide variety of state and federal statutes that permit the sharing of information and data directly related to the administration of programs authorized by the statutes. A cooperative effort is necessary among the Department of Health, Board of Education, and the Department of Social Services. The Central Registry needs to be governed by a Joint Coordinating Committee and managed by a Joint Cooperative Policies and Procedures Management Board with representatives appointed by each of the state agencies involved.

Organizational Structure of the Central Registry


People of the state through Statutes
Joint Coordinating Committee
Management Board
Central Registry Coordinator
Ad Hoc Committees Appointed by the Management Board With Approval of the Joint Coordinating Committee

The Management Board, with the advice and consent of the Joint Coordinating Committee, can:

1. oversee the general management of the registry and access to the data file,
2. ensure confidentiality of personally identifiable information contained in the data files,
3. develop and implement the formalized procedures of the registry,
4. ensure that legal requirements are met, and
5. handle grievances.

The Central Registry, then, provides a coordinated interagency management and information data system for the storage and use of confidential data required by the cooperating agencies for the administration of programs and research. The registry also provides data to assist in the development of agency-specific policies and comprehensive statewide planning needed to meet the needs of the developmentally disabled and handicapped.

POLICIES

1. Access to the interagency data file should be controlled by a Central Registry coordinator. Access needs to be carefully controlled by providing a password only to those individuals who have signed a confidentiality agreement and only for those purposes for which they are authorized. Restrictions for gaining access to the data file for purposes of administering programs specifically authorized in state or federal statutes

and applicable regulations promulgated thereunder should include the following:

a. Individuals should be identified by the Principal Administrator of programs. It is understood that supervisory personnel in such agencies authorized to provide programs to the handicapped and developmentally disabled shall be recommended. Supervisory personnel could include directors of local public health units, hospital administrators, director of special education programs in local education agencies, and administrative or supervisory personnel in the central office of the state agency responsible for the overall administration of programs authorized by state and federal statutes.

b. A listing for each individual describing which screens that individual will have access to and in what way they will be used along with names, positions, and current addresses of all individuals identified and recommended by the principal administrator shall be kept current.

c. No person should have access to the central registry data file until:

   1. a signed confidentiality agreement has been placed on file with the coordinator, and
   2. approval has been given by the management board.

d. Upon termination of employment with any contributing agency or organization, the principal administrator shall notify the coordinator immediately. Upon such notifications, the coordinator shall remove the individual's name from the approved list of persons who may access the data file and also remove from the file the password assigned to ensure that the file is no longer accessible.

2. Maintenance and operation of the Central Registry should be a function of the coordinator. The duties and functions of the coordinator could include:

a. Ensuring that any entry made by individuals authorized to enter personally identifiable information is not already in the file. When any question arises as a result of apparent discrepancies, the coordinator shall contact the agency (or agencies) providing differing information to confirm that such discrepancies are resolved and, to the extent possible, ensure that an unduplicated enumeration of persons is maintained in the data file.

b. Ensuring that information and data regarding any individual identified in the file can be changed only by the originating agency. Data entered by Health cannot be changed except by Health; data entered by the Office of Education cannot be changed except by Education; and data entered by Social Services cannot be changed except by Social Services.

c. Ensuring that search screens such as phonetic search screens designed to identify persons with names that are similar phonetically, but spelled differently, shall be accessed by predetermined administrative personnel and no other persons.

d. Designing a coded sign-on screen as an additional level of security of the Central Registry. Any authorized person shall have a password assigned and be familiar with the coded sign-on procedures before any data shall be available to such person.

DATA SCREENS

Several examples follow of typical data screens that could, and probably should, be included in a Central Registry. The screens are, of course, only examples and represent a small fraction of the total that would be necessary for implementation of a statewide system. However, they give an overall view of the power of such a system.

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1. Add New Client To Master screen.

```
XXX  XXXXXXXX                                    MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y     AGENCY: XX XXXXXXXXXX
                ADD NEW CLIENT TO MASTER SCREEN

CLIENT NAME (LAST, FIRST, MI): ____________________________
CLIENT ADDRESS LINE 1:         ____________________________
CLIENT ADDRESS LINE 2:         ____________________________
CLIENT CITY, STATE, ZIP CODE:  _____________ __ _________

MARITAL STATUS _  SEX: _  SSN: ___ __ ____ BRTH-DATE(YMD):__ __ __
BIRTH PLACE (CITY, STATE): _____________ ETHNIC CODE:  _

RESIDENCE CODE: _  COUNTY: __  SCHOOL DIST: __  SCHOOL LOC: ___

CONTACT PARTY CODE: _
CONTACT PARTY NAME (LAST, FIRST, MI): ____________________________
CONTACT PARTY STREET ADDRESS:         ____________________________
CONTACT PARTY CITY, STATE, ZIP CODE:  _____________ __ _________

CONTACT PARTY LEGAL GUARDIAN? _      GUARDIAN CODE:  _
LIVING ACCOMODATIONS CODE:    _      LIVING ACC DESC: _____________


MESSAGE AREA:_____________________________________________________________
```

2. Inquiry Data Menu which allows quick entry into special reports relating to interagency involvement.

```
XXXX  XXXXXXXX                                   MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y     AGENCY: XX XXXXXXXXXX
                  ---- INQUIRY DATA MENU ----

          00.  RETURN TO MASTER MENU
          01.  INQUIRY DEMOGRAPHIC / CONTACT PARTY DATA
          02.  INQUIRY CASE STATUS DATA
          03.  INQUIRY AGENCY PROVIDING DATA SECTION
          04.  INQUIRY CASE MANAGER DATA
          05.  INQUIRY DEVELOPMENTAL/FUNCTIONAL LEVEL DATA
          06.  INQUIRY INTER-AGENCY REQUEST FOR FURTHER SERVICES DATA
          07.  DISPLAY INTER-AGENCY COMPARISONS - DEVELOPMENTAL DATA
          08.  DISPLAY INTER-AGENCY COMPARISONS - DISABILITY DATA

               ENTER SELECTION: __




      WORK KEY:  LAST NAME        SEX   BIRTH-DATE        SSN
                 XXXXXXXXXXXXXXX  X    XXXXXX            XXX XX XXXX

  MESSAGE AREA:_____________________________________________________________
```

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3. Case Manager Data By Agency screen allows easy access to the contact person in each agency for any individual client.

```
XXXX  XXXXXXXX                                        MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y          AGENCY: XX XXXXXXXXXX
          CHANGE CASE MANAGER DATA BY AGENCY SCREEN
CLIENT NAME: XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX  X  XXXXXX  XXXXXXXXX


                 SOCIAL SERVICES                    HEALTH SERVICES
  NAME:          XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX    XXXXXXXXXXXXXXXXXXXXXXXXXX
  ADDRESS:       XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX    XXXXXXXXXXXXXXXXXXXXXXXXXX
  CITY,ST,ZIP:   XXXXXXXXXXXXXXX  XX  XXXXXXXXX    XXXXXXXXXXXXXXXXXXXXXXXXXX
  ID NUMBER:     XXXXXXXXXX                         XXXXXXXXXX

                 DEPART OF EDUCATION                OTHER DEPARTMENT
  NAME:          XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX    XXXXXXXXXXXXXXXXXXXXXXXXXX
  ADDRESS:       XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX    XXXXXXXXXXXXXXXXXXXXXXXXXX
  CITY,ST,ZIP:   XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX    XXXXXXXXXXXXXXXXXXXXXXXXXX
  ID NUMBER:     XXXXXXXXXX                         XXXXXXXXXX


    ENTER 'Y' TO RETURN TO -----> MASTER MENU: _  CHANGE MENU: _
  MESSAGE AREA:_____________________________________________________________
```

4. Change The Developmental/Functional Level Data screen allows any of the agencies to change developmental levels for each individual client as they may changes due to age, surgery, education, etc.

```
XXX  XXXXXXXX                                         MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y          AGENCY: XX XXXXXXXXXX
          CHANGE DEVELOPMENTAL/FUNCTION LEVEL DATA
CLIENT NAME: XXXXXXXXXXXXXXXXXXXXXXXXXXXXXX  X  XXXXXX  XXXXXXXXX
 ENTER 'Y' BY ITEMS THAT CLIENT CAN/HAS:          DD ELIGIBILITY FLAG: _
 X CARE FOR SELF          X RECPTVE/EXPRSSVE LANG      X LEARN
 X AMBULATE               X LIVE INDEPENDENTLY         X DIRECT SELF
 X ECONOMIC SELF SUFF

 ENTER 'Y' BY ITEMS THAT CAN BE REMEDIATED:
 X SELF CARE              X LANGUAGE PROBLEM           X ABILITY TO LEARN
 X MOBILITY PROBLEM       X INDEPENDENT LIVING         X SELF DIRECTION
 X ECONOMIC SELF SUFF     WILL CONDITION LIKELY TO CONTINUE INDEFNTLY: _
 PROGNOSIS DATE: XX XX XX  PROGNOSIS MADE BY: X   DESC: XXXXXXXXXXXXXX_

 -- DISABILITY SECTION --
 DIAGNOSIS FROM CODE: X DESC: XXXXXXXXXXXXXXX  DATE: XX XX XX PLCMNT: X
 X MENTALLY RETARDED?     X CEREBRAL PALSY?            X EPILEPSY?
 X AUTISM?                X SPINA BIFIDA?              X MUSCULAR DYSTROPHY?
 X AT RISK/DEV DELAY?     X SIGNIFICANT HEARING?       X SIGNIFICANT VISION?
 X SGNF SPEECH/LANG?      X EMOTIONAL/BEHAVIOR?        X CHRONIC MEDICAL PR?
 X NON-AMBULATORY?        X DYSLEXIA ?                 OTHER: _____________
 ENTER 'Y' TO RETURN TO  -----> MASTER MENU: _    CHANGE MENU: _
MESSAGE AREA: ____________________________________________________________
```

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5. Change Recommended Service Needs By Other Departments screen allows the prompting of referral agencies by the originating agency of a particular client's needs.

```
XXX  XXXXXXXX                                        MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y        AGENCY: XX XXXXXXXXXX
     CHANGE RECOMMENDED SERVICE NEEDS BY OTHER DEPARTMENTS
CLIENT NAME: XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX  X  XXXXXX  XXXXXXXXX

---REQUESTING DEPARTMENT DATA---   -----ACKNOWLEDGING DEPT DATA----
DEPARTMENT      DATE   INITIALS    CD DEPARTMENT      DATE   INITIALS
HEALTH SERVS  XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX

EDUCATION     XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX

SOCIAL SERVS  XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX

OTHER DEPTS   XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
              XXXXXX    XXX        XX XXXXXXXXXXXX   XXXXXX   XXX
 ENTER 'Y' TO RETURN TO ------> MASTER MENU: _   CHANGE MENU: _
MESSAGE AREA: ____________________________________________________
```

6. Inter-Agency Disability Comparison Display screen allows the quick identification by any agency, but by particularly the responsible agency of the client's disabilities. If there is a discrepancy among agencies, that clearly is identified and might lead to additional diagnosis.

```
XXX  XXXXXXXX                                        MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y        AGENCY: XX XXXXXXXXXX
       INTER-AGENCY DISABILITY COMPARISON DISPLAY
CLIENT NAME: XXXXXXXXXXXXXXXXXXXXXXXXXXXX  HEALTH EDUCTN SSRVCS OTHER
01. MENTALLY RETARDED?                        X      X      X      X
02. CEREBRAL PALSY?                           X      X      X      X
03. SEIZURE DISORDER/EPILEPSY?                X      X      X      X
04. AUTISM?                                   X      X      X      X
05. SPINA BIFIDA?                             X      X      X      X
06. MUSCULAR DYSTROPHY?                       X      X      X      X
07. AT RISK/DEVELOPMENTAL DELAY?              X      X      X      X
08. SIGNIFICANT HEARING IMPAIRMENT?           X      X      X      X
09. SIGNIFICANT VISION IMPAIRMENT?            X      X      X      X
10. SIGNIFICANT SPEECH/LANG PROBLEM?          X      X      X      X
11. EMOTIONAL/BEHAVIORAL PROBLEM?             X      X      X      X
12. CHRONIC MEDICAL PROBLEM?                  X      X      X      X
13. NON-AMBULATORY?                           X      X      X      X
14. SEVER LEARNING DISABILITY (DYSLIXIA)?     X      X      X      X
15. OTHER CONDITION?                       XXXXXX XXXXXX XXXXXX XXXXXX
16. MEDICAL DIAGNOSIS CAME FROM CODE          X      X      X      X
17. MEDICAL DIAGNOSIS DATE (YYMMDD)        XXXXXX XXXXXX XXXXXX XXXXXX
18. CURR SCHOOL PLACEMENT CODE                X      X      X      X
 ENTER 'Y' TO RETURN TO ------> MASTER MENU: _    INQUIRY MENU: _
MESSAGE AREA: ____________________________________________________
```

7. Interagency Prognosis Comparison Display screen allows a comparison of each agency's prognosis for individual client. The importance of this screen cannot be underestimated.

```
XXX  XXXXXXXX                                        MM/DD/YY   HH:MM:SS
                    U R D D   R E G I S T R Y        AGENCY: XX XXXXXXXXXX
          INTER-AGENCY PROGNOSIS COMPARISON DISPLAY
CLIENT NAME: XXXXXXXXXXXXXXXXXXXXXXXXXXXX  X  XXXXXX  XXXXXXXXX
    DD ELIGIBILITY FLAG : _  _  _  _        HEALTH EDUCTN SSRVCS OTHER
01. PROGNOSIS DATE (YYMMDD):                XXXXXX XXXXXX XXXXXX XXXXXX
02. PROGNOSIS MADE BY CODE OR DESCRIPTION:  XXXXXX XXXXXX XXXXXX XXXXXX
03. CAN CARE FOR SELF?                      X      X      X      X
04. HAS RECEPTIVE/EXPRESSIVE LANGUAGE?      X      X      X      X
05. CAN LEARN?                              X      X      X      X
06. CAN AMBULATE?                           X      X      X      X
07. CAN LIVE INDEPENDENTLY?                 X      X      X      X
08. CAN DIRECT SELF?                        X      X      X      X
09. IS ECONOMICALLY SELF SUFFICIENT?        X      X      X      X
10. CAN SELF CARE BE REMEDIATED?            X      X      X      X
11. CAN LANGUAGE PROBLEM BE REMEDIATED?     X      X      X      X
12. CAN ABILITY TO LEARN BE REMEDIATED?     X      X      X      X
13. CAN MOBILITY PROBLEM BE REMEDIATED?     X      X      X      X
14. CAN BECOME CAPABLE OF INDPNDNT LIVING?  X      X      X      X
15. CAN BECOME CAPABLE OF SELF DIRECTION?   X      X      X      X
16. CAN BECOME ECONOMICALLY SELF SUFF?      X      X      X      X

 ENTER 'Y' TO RETURN TO ------> MASTER MENU: _    INQUIRY MENU: _
MESSAGE AREA: ____________________________________________________________
```

## SUMMARY

It is hoped that these examples of data bases for program collaboration are consistent with the philosophy engendered by most agencies and states. They will provide for (1) appropriate utilization of data processing resources, (2) the return of a high yield on the state's investment for securing data essential to the effective and efficient delivery of services to the developmentally disabled and handicapped population, and (3) an unduplicated enumeration of this population for purposes of planning and allocation of available resources.

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